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ABSTRACT

This qualitative research study aimed to examine the nature of systems change and to identify practices and strategies that states, specifically New Hampshire, use to promote community integration and deinstitutionalization of people with developmental disabilities. The study describes the New Hampshire system, including state practices, characteristics, issues and problems, and historical and thematic areas. Thematic areas include the role of the courts, the role of state institutions, structural factors in community services development, family support, and self advocacy and guardianship. Community integration service practices have focused on family support, supported employment, community living and home ownership, self advocacy, case management, guardianship, and aging and developmental disabilities. The study highlights comparative roles of groups in the change process, including families, external advocates, state and community administrators, media, litigators, and legislators and policymakers. A framework for thinking about systems change is presented, which views community integration as a slowly evolving process with key "events" occurring along the way which significantly altered or shaped others that followed. Selected research areas and hypotheses are outlined. (Contains 95 references.) (JDD)

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**COMMUNITY INTEGRATION AND DEINSTITUTIONALIZATION:
CHARACTERISTICS, PRACTICES, AND COMPARATIVE ROLES
IN THE CHANGE PROCESS**

COMMUNITY AND POLICY STUDIES

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Julie Ann Racino

COMMUNITY AND POLICY STUDIES
Syracuse, New York

1993

This qualitative research study is based upon site visits to the state of New Hampshire conducted in Fall 1991 and Summer 1992, semistructured telephone interviews within and outside of the state, and a review of documents. It is the first of a series of indepth qualitative studies of state and national practices and the changes that will be necessary to promote the full participation of people with disabilities in all aspects of community life and daily policymaking.

ACKNOWLEDGEMENTS

This qualitative research report is the overview and summary of an edited collection of case studies designed to better understand the nature of systems change and to identify practices and strategies that states, such as New Hampshire, use to promote community integration and deinstitutionalization.

In many ways, it is a thank you to the fine people in New Hampshire who contributed to this extensive qualitative research effort. New Hampshire was the first of 35 technical assistance sites I worked with beginning in FY 1986-87 to assist in promoting community integration and community living for people with the most severe disabilities. I learned a tremendous amount from people within the state who were trying to do what they could to make life better for people who have not had quite the same chances in life as some of us.

Regarding this study, thanks are extended particularly to the many informants within and outside of New Hampshire who shared their views and insights. These include Sue Berube, Brian Blodgett, Ray Blodgett, Alan Blood, Bindy Bourgeois, Valerie Bradley, Lou Brown, Michael Cassassanto, Linda Coggeshall, Richard Cohen, Richard Crocker, Richard Crowley, Jean Delphia, Hillery Douglas, Alan Emerson, Jocelyn Gallant, Roberta Gallant, Judith Heumann, Jane Hunt, Janet Hunt-Hawkins, David King, Jay Klein, K. Charlie Lakin, Frank Laski, Richard Lepore, John MacIntosh, Lynda McAtee, Chris Nicolletta, Jan Nisbet, Joseph Norman Moses, Sandra Pelletier, Bev Perry, Mary Beth Raymond, Alan Robichaud, Marjie Rhodes, Sue Scott, Donald Shumway, Gary Smith, Patty McGill Smith, Norman Tanner, Dottie Tessier, Donald Trites, Frank Tupper, Dan Van Keuren, Sylvia Stanley, Nancy Ward, Leslie Washburn, Deirdre Watson, Doug Watson, Donna Woodfin, David Willett, Sheila Zakre, and others. Their insights are perceptive and informative, and I am hopeful others will benefit from them.

Particular notes of thanks also to these organizations, in addition to the State Division of Mental Health and Developmental Services and area agencies who participated in this study: Granite State Independent Living Foundation, the state's Protection and Advocacy Organization, the University of New Hampshire Institute on Disability, the state Association for Retarded Citizens, the state Developmental Disabilities Council, the newly formed Self Advocacy Association (People First of New Hampshire), and the New Hampshire Office of Public Guardian.

This work also benefitted from the insights of other researchers, as described in the methodology. They share the credit, and I assume responsibility for any issues or concerns that may arise. Extensive efforts of this kind involve contributions by many people, and special thanks are extended to the original research design advisory committee and to the national reviewers who took the time to read, comment and strengthen the edited collection. In particular, thanks are extended to the following for their direct and indirect contributions: Gary Smith, Charlie Lakin, Patti Smith, Nancy Ward, Frank Laski, Judith Heumann, Richard Hemp, Alan Abeson, Michael Kennedy, Perry Whittico, John O'Brien, Karan Burnette, David Hagner, David Merrill, Ginny Harmon, Freeda Smith, and Mary Hayden.

A personal note of thanks to my parents, relatives and friends, who supported the completion of the final stages of writing and as always, were there when it mattered. To each of you, I am very grateful. Thank you also to each of the individual people in different states for whom the case studies were written; I always write with particular people in mind and hope I can help in a small way with the constant challenges you face.

Julie Ann Racino
1993

NEW HAMPSHIRE DEVELOPMENTAL DISABILITIES SYSTEM

NEW DECADE, NEW DECISIONS

We have learned that most often what people with developmental disabilities need has little to do with their disability and a lot to do with the environment in which they live, work and play. They say they want opportunities to experience and choose those things in life that are not disability related. Yet all too often, due to their disability, their presence and participation in areas such as housing, employment, transportation and social relationships has been restricted.

All people need safe and secure homes. All people need gainful employment. Everyone - from infants to older Americans - needs permanent and caring relationships. By addressing the needs of people who have developmental disabilities, by shifting away from cumbersome formal and specialized services, we reduce the risk of separating people and services from the larger community of all individuals who need support. Resources need to support individuals not programs. Supports need to become more generic. Generic resources serve all people and are not limited to categorical application that is decided by the presence or absence of disabling conditions.

- From the booklet "dedicated to each and every one of New Hampshire's citizens who are taking part in the Granite State's 'Copernican Revolution'."

I. Introduction to the Policy Research

In the past decade, the mental retardation field has moved from research, training, and service framed by the debate of institutional versus community life to ways of supporting people with disabilities to be fully involved in regular homes, jobs, leisure and community (e.g., Bradley & Knoll, 1993; Hayden & Abery, 1994; Taylor, Racino & Walker, 1992; Towell, 1988; Wehman, 1993).

However, on the level of state policy research indepth studies of state systems remain scant (RTC on Community Integration for Persons with Mental Retardation, 1990). While a few case systems studies exist (e.g., McWhorter, 1986), most state policy studies focus on specific service programs or funding mechanisms within or across states (e.g., Kennedy & Litvak, 1991; Smith, 1990) or comparative studies of facilities or other research framed by the LRE model (e.g., Hill et al, 1989; Willer & Intagliata, 1982).

Deinstitutionalization has been a notable exception with more indepth studies exploring the richness of the individual's experiences (Conroy & Bradley, 1985; Edgerton, 1988; Lord & Hearn, 1987; Lord & Pendlar, 1991; Rothman & Rothman, 1984). A number of these studies also conceptually describe the meaning of community integration in practice, though often interpreting the data within the context of existing frameworks such as Nirje's (1980) levels of integration.

Many policy studies are methodologically based on telephone interviews and survey forms (e.g., Braddock & Mitchell, 1992; Knoll, Covert, Osuch, & O'Connor, 1992; Turnbull, Garlow & Barber, 1991), on relatively limited on-site observations (e.g., O'Brien & O'Brien, 1987, Reynolds, 1991) or are designed for specific formative or summative evaluation purposes (e.g., Taylor, et al, 1992; Racino et al, 1989).

Such studies are also often intended to serve the "world of action that governs the organization, process, funding and regulation of services" (Bruininks, 1990). Researchers may not view these studies as adding to the research knowledge base or advancing theory. This may be the case even when recognition is paid to the importance of the linkages between research, service, social movements and local, state, and national leadership (Menolascino & Stark, 1990).

Relatively little indepth applied knowledge exists from a qualitative research perspective about state practices in areas such as community integration and deinstitutionalization. Areas yet to be investigated include the nature of systems change, the relationship of state practices in community integration to individual life quality, and the nature of multi-level (state, regional and local) interactions. Many of the research questions (e.g., how new ideas come to capture the attention of policymakers)

also have relevancy in the public policy research arena.

A. Research Methodology

This policy research study was designed to examine the process of state change in deinstitutionalization and community integration. The first purpose was to identify and describe practices and strategies that states use to promote community integration and deinstitutionalization (Taylor, 1990). The second was to better understand the nature of systems change and its relationship to individual life quality (Racino, 1991).

The policy research study reflects a more indepth and systematic version of state evaluation research studies (Racino, O'Connor, Shoultz, Taylor, & Walker, 1989; Taylor, Racino, & Rothenberg, 1988; Taylor, Racino, Walker, Lutfiyya & Shoultz, 1992; Taylor, Racino, Knoll & Lutfiyya, 1987) developed as part of a national technical assistance effort on community integration with 35 states in the US.

The policy research methodology has an interdisciplinary focus that draws on the disciplines of political science, sociology, psychology, anthropology, rehabilitation and other applied disciplines (Majchrzak, 1984; McCrae, 1980; Willigen, 1986). This methodology builds upon a long history of qualitative research studies, particularly in the field of mental retardation and is directed toward solving applied problems in the field (Brooks, 1979; Taylor & Bogdan, 1984; Weiss, 1978).

The study relies on in-person semi-structured interviewing rather than participant observation techniques (Patton, 1980), and is based on an empirical-inductive approach, indicating that the findings emerge from and are grounded in the research data (Nosek, 1992). It relies heavily upon a multiple case study design (Yin, 1989), including cross-study analyses. More indepth information describing this research methodology, particularly in the state of New Hampshire, is contained in a separate report¹.

B. Research Findings

This 1993 summary on community integration and deinstitutionalization provides an overview of policy research findings based upon data collected in the state of New Hampshire. Section II describes the New Hampshire system, including state practices, characteristics, issues and problems, and historical and thematic areas. Section III highlights comparative roles in the change process and presents one framework for thinking about systems change based upon the perspectives of the research informants.

¹ The reader can request a separate report on the methodology regarding the policy research for the state of New Hampshire.

II. The New Hampshire Developmental Disabilities System

This section includes five parts: an overview of state characteristics relevant for understanding the systems change process in New Hampshire; community integration practices; state issues and problems; a brief history of the development of the New Hampshire service system, together with a key events timeline; and an overview of thematic areas from the study.

A. New Hampshire State Characteristics

The state of New Hampshire is considered to be one of the most conservative states in the US. Located on the northeastern seaboard, it has no state income tax or sales tax and a strong belief in local control with minimal governmental intervention. Concord North is agricultural and divided by the mountains, and Concord South is more densely populated and "high tech" and located near the Boston corridor.

The concept of moving away from service systems and back to communities is a politically conservative notion. So while New Hampshire has moved in a direction considered progressive in the disability field, the movement toward communities is consistent with the "grain of a place like New Hampshire." They have indeed managed to accomplish "a great deal with relatively little money."

Five primary themes were critical in analyzing the nature of systems change in the state of New Hampshire. These included its small size, shared values base, state leadership and continuity, reasonable working relationships, and commitment to change.

Small size. The state is small both geographically and in terms of population. In relationship to change strategies, this means that few people are involved in the developmental disabilities field. An "informal" talk network develops which makes it easier to achieve agreement and to have both "official" and "unofficial" positions, including on controversial issues. People learn quickly who can be trusted; small efforts can have very large impacts and the "best people" in the state can be brought together to personally address the most challenging situations.

Shared values base. Participants within the developmental disabilities system generally share a common values base and more emphasis is placed on the areas of agreement than on differences in degree, emphasis, kind or position "on the road." There is a widespread belief that people are "headed in the same direction."

State leadership and continuity. The continuity in key positions in sectors ranging from the advocacy community to the state administration has been extraordinary. In spite of the small size, there are opportunities for people in all different sectors to play leadership roles, including at the state office, the university,

the regions, family groups, advocacy organizations, and in the fledgling self advocacy movement.

Reasonable working relationships. A highly significant factor has been the degree of cross-collaboration that has occurred over time. As an outsider, familiar with many states, shared: "The spirit of collegiality is extraordinary." Whether termed team, family or collaborators, there is a real "solid group of people" who generally believe that each other "care" and "want to do better" even when things go wrong. This does not mean, of course, that "squabbles" or "battles" do not occur.

Commitment to change. As the field changed, in New Hampshire, people tried to change too, not in the sense of following a fad, but of genuinely attempting to shift the system in that direction. They never became locked in one phase, and remained open to an interactive planning process of change. Concepts changed so rapidly in the disability field that a planning notion needed to be open ended about the future and the assumptions upon which it was based.

B. Brief History of the New Hampshire Service System

Twelve or thirteen years ago, "there was no community service system to speak of in New Hampshire." In 1979, the "system" consisted primarily of a "collection of sheltered workshops and (other) things started by parent groups, really that's all there was, not a whole lot." Or as yet another informant expressed, "there was no regional system just "Laconia then nothing, except a couple of group homes."

The earliest community services were started largely by parents who visited Laconia, the state institution, and were "devastated by what (they) thought was the warehousing of people." They banded together with other parents, found volunteers, renovated or leased buildings, and developed the first school programs. Some of these parents then formed local chapters of the Association for Retarded Citizens, later joining the state association.

The basic law governing the developmental disabilities service system RSA-171A was written in 1975, and has not been substantially changed since, except for modifications in the definition of developmental disabilities. The legislation called for the establishment of an area agency system and also provided for individual assessments and evaluations, "all that kind of standard terminology that nobody could figure out in 1975, but we all were committed to."

In the mid-70s, special education law (PL 94-142), with the advocacy of groups such as New Hampshire's Coalition for Handicapped Citizens, was passed and implemented in state policy

translations. Even though focused on children from birth through twenty one, these principles translated to adults, helping to create a vision of what was possible. Later, in the 1990s, adult services would begin to give back to special education the next vision of the future.

Led by the New Hampshire ARC, in 1978, a class action lawsuit was filed by the residents of Laconia, the state institution. After a public trial, a court order followed in 1981. The lawsuit came about because "two parents faced each other and realized that things were bad and something had to be done." The parents enlisted the support of New Hampshire Legal Assistance and the Department of Justice later joined the effort. The basic state plan, Action for Independence, was accepted by the court. The key people involved within the state office/planning council in writing the plan remained as part of the implementation process over the next decade.

In the late 1970s, in addition to parent advocacy, organizations such as the state's Protection and Advocacy office were formed. The independent guardianship program, still considered to be developed through a "model statute," was written and implemented.

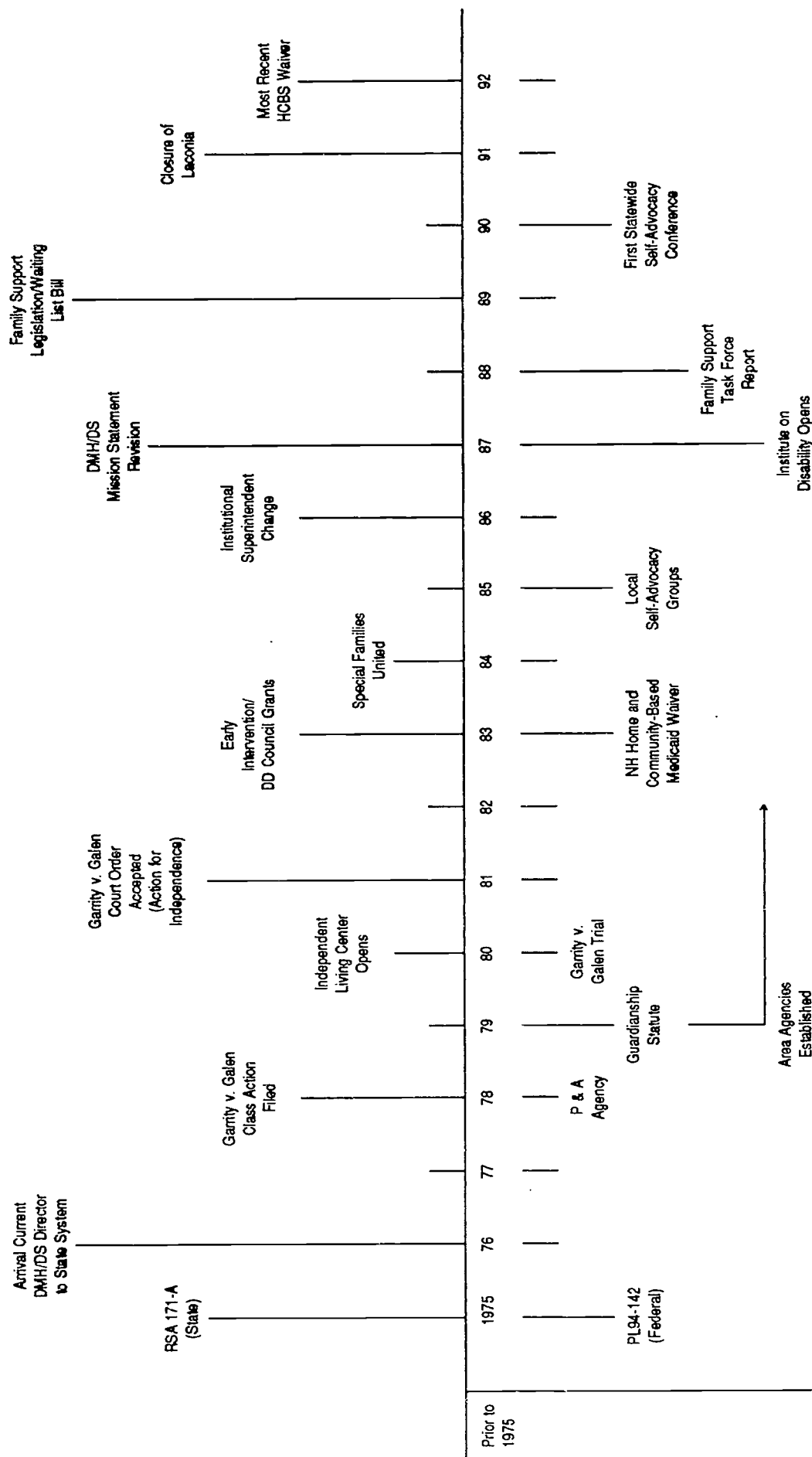
The next decade was marked by "an increasing sophistication and refinement of the service system, particularly in the way finances are handled, how services get paid for." New Hampshire successfully accessed the Medicaid home and community-based waiver (PL 97-35) for community services starting in 1983. In 1991, it had the highest per capita funding and highest percentage of service recipients in the Federal waiver program compared to any state (NH Office of Legislative Budget Office, 1991). As of 1993, New Hampshire ranked sixth in the number of people participating in the program per 100,000 of the general population and 4th in per capita spending on their behalf (Smith & Gettings, 1993). For all practical purposes, the New Hampshire community service system is built upon this financing.

While New Hampshire has moved in a direction considered progressive in the disability field, it is consistent with the conservative, community nature of the state. In the course of the decade, in spite of the adversarial roles inherent in the court trial, there was relatively little fragmentation in philosophy and direction across groups, whether advocacy groups, area agencies, or the state office. Although people differed on and fought about the particulars, to a large extent, people "hung together" moving in the same general direction with a commitment toward community life.

The statistics on New Hampshire support this consistent effort over an extended period to shift focus from institutional to community living for people with developmental disabilities. Over

KEY EVENTS TIMELINE (NEW HAMPSHIRE)

Figure 1.



the period of 1977 to 1988, New Hampshire moved from the 25th place among states in community services spending to eighth, while institutional spending remained constant (University of Illinois-Chicago, 1992). In that same period, its public institutional population decreased by 50% and its nursing home useage remained low (University of Illinois-Chicago, 1992).

By fiscal year 1990, the area agency community system spent \$59 million and served 3,218 clients at an average cost of \$18,400. On a statewide basis, in 1990, area agencies employed 974 full-time equivalent staff members and contracted with approximately 80 providers of services (NH Legislative Budget Office, 1991).

The philosophy and expectations regarding community life shifted in New Hampshire as they have throughout the country to varying degrees. While this was an "evolutionary process," there were also times when "all of a sudden" a "leap of faith" was made that allowed people to move to a new set of beliefs and practices that were previously seen as "unrealistic." These times, while harder to pinpoint by date or event, are nonetheless real and critical and involve a "commitment and trust to a more integrative community life."

In 1989, the concept of regional family support councils was established in New Hampshire Laws, Chapter 255 (RSA 126-G), following a report by a legislative task force on family support and grassroots organizing. These councils, one in each of the 12 regions, are a concrete representation of a beginning shift in the state to a new constituency base of families versus the traditional constituencies of state institutional and community employees.

People with mental retardation, with assistance from organizations such as the state ARC and the New Hampshire Developmental Disabilities Council, formed People First of New Hampshire. In 1990, a statewide self advocacy conference was held and a contingent from New Hampshire traveled to the national conference in Tennessee. The Lakes Region self advocacy group, which grew out of a previous state effort, was one of the earliest local groups formed in the mid-80s.

Laconia State School closed its door on January 31, 1991, making New Hampshire the first state in the United States without a public institution for people with developmental disabilities. The closure itself was accomplished by people in a variety of sectors working together, including the Division of Mental Health and Developmental Services, the Area Agencies, the advocacy community and staff from the institution itself.

While there is general agreement that the court order was essential for closure to occur, one of the less well known turning points was the contributing role of the new institutional superintendent at a time when there were "no legal handles." The

institutional staff within worked together with their community counterparts toward the closure. By the time it occurred, for all practical purposes, the area agency directors had the attitude that "nobody would go back to Laconia...and everybody would struggle how to put things together so that didn't happen."

Today, New Hampshire is facing new issues, since the major motivating force of movement from the institution to the community has now to a large extent been achieved. As discussed in New Decades, New Decisions, which explains the current mission:

We'll know when we've been successful when there is evidence that people with disabilities are participating in their community, working at meaningful jobs, involved in integrated employment situations and enjoying the simple opportunities for life and recreation the rest of the world take for granted.

C. Thematic Areas in the New Hampshire Policy Research

The following summarizes the five major thematic areas identified for further study during the initial site visit. These also represent historical, overlapping time periods where the focus and emphasis for that period began to shift, though still remaining as an active force.

Garritty v. Gallen: Role of the courts in institutional closure.

From 1977 through the present, this class action litigation was a central force in institutional closure and community development in the state of New Hampshire. Key factors surrounding the litigation identified as contributing to its positive outcomes were: poor institutional conditions, a "clean slate" in the community; the timing of the litigation, and the modeling on Pennhurst; the public nature of the trial, including the role of outside experts; the nature of the class of plaintiffs, and the lack of a court master or monitor.

Cooperation across sectors was also key and was facilitated by the commitment of the plaintiffs' lawyers, the involvement of the Department of Justice, the courage and tenacity of the parents, leadership of state planners, the wisdom of the judge, regional support by area agencies and the minimal organized opposition (Racino, 1993a).

Closing of Laconia, the state institution.

From 1986 until its closure on January 31, 1991, a series of internal practices occurred that contributed to New Hampshire becoming the first state without a public institution for people with developmental disabilities in the United States. These internal management practices included major revisions in the

personnel system; repeated restructuring and reorganization during downsizing; practices for caring for and about staff and maintaining institutional quality during the closure process.

The programmatic practices included reinvigorating the placement process; building trust and sharing expertise between the community and institutional systems; shifting community attention to people in the institution; and focusing on individuals and their support needs. Significant external factors included the lack of a formal closure plan and the shift from institutional to community financing. (Racino, 1993b)

Structural factors in community services development.

Beginning in the late 1970s through the present, three critical structural features were central to the development of the community services sector. These included: the twelve area agencies which were established between 1979-83, the home and community-based Medicaid waiver begun in 1983, and state and federal roles and their effect in regulation.

The area agencies "work" due to the focus on local control, including the capacity to mobilize community support; the flexibility to respond to regional variations; the tension between the state and regional roles resulting in a "negotiated" relationship; and funding stability and flexibility when combined the waiver, in addition to other factors.

The home and community-based (HCB) Medicaid waiver is the major financing upon which the service system is built and has the flexibility to respond to changes in philosophy and practice that occur rapidly within the field. Medicaid active treatment and health and safety regulations are the primary barriers faced by the state (Racino, 1993c).

Family support, legislation, and councils.

The formation of parent groups predated the mid-1970s development of the service system and the Garrity v. Gallen legal actions. The family task force and family support bill occurred in the 1988-1990 period with the councils now in operation statewide. (For case study report, see Shoultz, 1993².)

Self advocacy, guardianship and personal perspectives.

In the mid-1980s, people with developmental disabilities

² For copy of this report (Shoultz, B. (1993). Like an angel they came to help us: The origins and workings of the New Hampshire family support system), contact NARIC, 8455 Colesville Rd., Suite 935, Silver Springs, MD 20910.

started forming groups on the local level, though the state's independent living center, Protection and Advocacy agency, and Office of Public Guardian had been in existence since late 1970s-early 1980s. The fledgling efforts in the state in self advocacy resulted in an in-state sponsored conference in 1990 and the establishment of People First of New Hampshire.

Decisions and concerns of people with developmental disabilities not always represented in policy studies include: marriage and family; jobs including career advancement and work disincentives; housing and places that suit people needs; freedom of movement; transportation; adult education; follow through on individual planning; and personal clothing and equipment.

Two concerns of professionals beginning to intersect with self advocacy efforts are guardianship and the distinctions between professional and personal viewpoints. Personal perspectives, understanding social change from the effect on an individual, includes knowing the nature of control through rule changes, differences regarding best interest and personal choice, foundation of life experiences and context, and the distinction between planning and individual effect (Racino, 1993d).

D. New Hampshire Community Integration Practices

Seven major community integration service practices were central in relationship to current changes in the state: family support, supported employment, community living and home ownership, self advocacy, case management, guardianship, and aging and developmental disabilities.

Family support. In the early 1990s, this represented the primary area of current energy and change. Each region has a family support council which relates to the area agency, but is distinct from it. Probably more than anything else, the state division was trying to promote a "family support attitude", that "ownership" of the system belongs to the families.

Supported employment. This was New Hampshire's first "individualization of programs" in the 1980s and was viewed as a demonstration of what people could do. Learnings than transferred to other areas.

Community living and home ownership. The University of New Hampshire has one of the Administration on Developmental Disabilities' A Home of Your Own Projects, which was in its very early development. A few agency efforts existed to promote family and community connections, experiences with people with severe disabilities sharing apartments and homes, and beginning changes in staff roles.

Self advocacy. The arc and Developmental Disabilities Council

provided support for self advocacy, including a statewide 1990 conference. New Hampshire People First now formed.

Case management. One region was an early federal demonstration site for case management. Not all regions separate case management from the agency providing services. Other safeguards include the promotion of internal advocacy roles.

Guardianship program. The New Hampshire program has a number of characteristics that make it unique across the states. These include independent versus case management model of guardianship, use of a functional versus a medical definition of incapacity, and heavy reliance on limited instead of full guardianship.

Aging and developmental disability. In contrast to age integration, the Division ascribes to the national movement of "cross generational community participation of people with all ages." This means that everyone lives and participates together, regardless of age, in community life, whether housing, recreation or political life. The Division has linked with other organizations, such as the American Association of Retired Persons, Housing and Urban Development and the Administration on Aging.

E. New Hampshire State Issues and Problems

Eight major state issues and problems were identified as areas to address to further community integration in the state. These include longstanding issues (e.g., payment for education), those in which positive steps are being taken (e.g., children in out-of-home placements) and emerging ones in this state (e.g., new population groups).

Educational system. Three areas of concern are funding education through local property taxes, especially in small towns, need for better information on the educational rights of parents in this "entitlement" system, and more accessibility and relevance of adult education, including changes proposed in the Individuals with Disabilities Education Act (IDEA).

Supporting children. The state has little experience with permanency planning, including foster care and adoption as components of a comprehensive system for supporting children to maintain permanent relationships with adults. New efforts, though, in returning children home from expensive out-of-state placements, were occurring.

The waiting list. People are still not getting all of what they need; they may be living at home without services, with elderly parents, or in the "back woods" depending on the "kindness of other people in town." The waiting list issue was highlighted in the 1992 report of the New Hampshire Office of the Legislative Budget Assistant.

Community transportation. Public transportation is not easily accessible, convenient or even available for people, including those with disabilities, who need to rely on it to participate in community life.

Institutional concerns. While very little transinstitutionalization (i.e., movement to other institutions) has taken place, a number of ideological compromises needed to occur. For example, one ICF-MR was developed as part of the closure process. There is still a private institution in the state; a few people live in county or state homes for elders, a few people in state hospitals, and some in "age inappropriate" situations.

Restructuring community services. New Hampshire is examining ways to move from facility-based services toward supported employment and is also "breaking down the group homes." However, it is difficult to "keep going what you have, develop what is new, and then move to the new" without additional resources. Reportedly, generic housing resources and subsidized financing are both underutilized. As of 1992, 60 of 125 properties funded by the Division were owned by area agencies and mostly financed by banks at commercial lending rates.

Family support and Part H. Family support as reflected in federal Public Law 99-457, the Early Intervention Program for Toddlers and Infants with Handicaps, was described as tending to be service oriented, deficit-based, professionally controlled, and based on a developmental framework. This contrasts with the intent of New Hampshire's early family support which focuses on support to participate in neighborhoods and communities.

New population groups. Particularly in the area of family support, people are reflecting on ways to address the needs of new population groups, including people with head injury and significant emotional needs, especially during a time of scarce resources. As one state official said:

What we really have to be about here is not a human service social system, but really changing how society, in general, responds to its people...And that's got to be for everybody. It can't just be for dd folks.

III. Learning about Change and the Change Process

This section includes two primary sets of findings. The first set describes the roles of groups and organizations in the community integration change process based on the data collection for New Hampshire. The second presents an overview of one theoretical framework for considering how change occurs based on the perspectives of the key research informants.

A. Key Leadership Components in New Hampshire

As background for a discussion of comparative roles in the change process, the following briefly highlights the key leadership components in the developmental disabilities system in the state of New Hampshire.

Division of Mental Health and Developmental Services (DMH/DS) is statutorily responsible for a comprehensive service delivery system for people with developmental disabilities in the state. It develops and manages the system through contracts with 12 regional private, non-profit organizations and maintains communication with the legislature, Governor, area agencies, communities and families.

Family leadership. In addition to the Association for Retarded citizens (now the arc), other family groups such as Special Families United have come into existence for periods of time. A family leadership series, sponsored by the Institute on Disability, brought together diverse families. The family support task force led to the state's family support legislation and family support councils, where families are playing new leadership roles.

Area agencies may provide services directly or contract with vendors for services such as case management, employment, habilitation, family support and residential. They are the primary recipients of state funds and responsible for an internal program of quality assurance. The New Hampshire system cannot be understood without knowledge of how these area agencies work.

Institute on Disability, now the university-affiliated program at the University of New Hampshire was created by the leadership in the state in the late 1980s. The functions of the UAP include bringing additional resources into the state, leveraging change as an "outside catalyst and conscience," serving as a training resource, and pushing, especially the education system in positive directions.

Advocacy organizations. A functional system of external advocacy exists in New Hampshire with long term leadership in roles such as the protection and advocacy organization and the Office of the Public Guardian. Other catalysts include the Developmental Disabilities Council, the Disability Rights Center, and the Alliance for Values Based Training.

Institutional leadership. The superintendent who started at the institution in 1985 was "brave" and spoke out against the institutional conditions. The second, arriving in the mid-1980s, is credited with transforming the values base in the institution, an action which played a pivotal role in closure. The union and staff within worked toward closure, and the institutional parent group, a branch of the ARC, continued into the community as a watchful safeguard.

Legislature. The state legislature is distinct in being one of the "largest legislative bodies in the world" with "400 people in the House and 24 Senators." This means that almost everyone personally knows a legislator and may even themselves end up being one someday.

B. Comparative Roles In The Change Process

This section highlights strategies for change by role and function based on experiences within the state. This overview can be used as one framework for systematic investigation of similarities and differences across the states. The primary intent is to examine effective roles that can be played by organizations and groups located inside and outside of the system to better promote practices in community integration and deinstitutionalization.

Family leadership: Traditional grassroots organizing

The actions surrounding the passage of the family support legislation were "pretty traditional organizing." These efforts were notable because they were done well, at the "right" time, with the "right" people, and with broad-based support for the desired outcomes. The strategies used (e.g., invite legislators to meet your child, write personal letters, telephone trees, thematic balloons, "coffee klatches") were aimed at personalizing the issues and keeping people involved, while still doing a "professional job."

People worked together on the legislation, instead of spending time and energy arguing about details. The family support legislation was paired with a waiting list bill, which had the effect of uniting the older and younger parents. New coalitions were formed as part of the process, inclusive of families who were not previously affiliated with any organization. The standard grassroots organizing techniques worked effectively, especially when combined with help from people working from within.

Role of external advocates: "Keeping things honest and on track"

External advocacy by parents was critical to the start of a massive systems change involving consciousness raising, the development of the community services system, and changes in the institution. Such advocacy was insufficient, however, in itself for the development of the community system or for the closure of the institution, both of which required "committed" allies from within to achieve their mutual goals.

Roles of external advocacy included keeping "things honest and on track" - a built-in tension that helped to move things forward and to assure that people would not become complacent with

what existed. Advocacy also served as a safeguard to keep the "floodgates from opening on something that's terrible." Like the media, external advocacy tended to concentrate on addressing the negative or problematic aspects both in the institution and in the community.

Role of state and community administrators: Progressive leadership

State and local leadership played a critical role in the change processes, whether in institutional closure, community development, family support or other areas. As an advocate explained, major systems change would not have occurred without "really progressive people at the state level...the most progressive state agency and...by and large, very progressive community directors."

Whether as civil servants or political appointees, the state leadership developed, influenced and shaped policy, and managed the system over the course of its development. Essential functions beyond a management view of their roles, included keeping a consistent message out in the field, supporting choice and experimentation, spending time with people who were doing the work, supporting community leaders and working with them, effectively solving problems, and helping people move along toward "real system change."

Role of the media: "Consciousness raiser"

The media in New Hampshire, particularly surrounding the court order and expose, played the role of "consciousness raiser" and "muckracker." The original stories on the court order were described as "a masterpiece unveiling of what the story was, what the issues were and what could be." This set the stage for an editorial position for the newspapers and media that was very supportive of change from institutional to community life.

The major perceived role of media was to "be a force to help us pinpoint really negative things." The media can influence behavior in both positive and negative ways, since "everybody lives in mortal terror of something getting into the papers." While the media's role was viewed as critical in the overall portrayal of people with disabilities, enlisting the help of the media in other than anecdotal ways was described as difficult.

Role of litigation in change: External pressure to "do the right thing"

Litigation appears to minimally have the following roles in change: it provides the external pressure necessary to obtain resources to make changes that the bureaucracy itself may want to do, but are unable to; it is a consciousness raising tool both about serious problems that exist and potential solutions; it can

lead to legislation and other policy changes that might not otherwise occur; and it can clarify and strengthen the values of those who participate in the litigation process, particularly as a witness. The litigation around Laconia in New Hampshire was a "catalyst" to the evolution of the community system and also was considered essential to the closure of the institution. It was an active force for over a decade.

Role of legislation and policy in change: Baselines and expectations

The three most important legislative/policy pieces in New Hampshire that historically have proven significant are the state law RSA-171A which established the developmental disabilities services system, the state's special education law, and Action for Independence, the major planning document which embodied the planning concepts of the federal Developmental Disabilities Act.

RSA 171A has stood the test of time over 15 years without becoming totally dysfunctional. The translation of PL 94-142, the "special ed law", was also critical since it "gave people hope and excitement," provided for due process, and was the clearest embodiment of civil rights that set an "expectation baseline."

In this study, legislation and policy were the likely result or product of an effective change process, versus the primary precursor events for major changes. They appeared to occur in the middle of the process, after issues are recognized, support was mobilized, and significant personal change and consciousness raising had occurred. Policies that simply emanated from the state office without tangible discussion are viewed as often leading to dissension and as a barrier to change.

Role of legislature and shifting power base: The future power balances

From the beginning, professionals and parents approached the New Hampshire legislature on the basis of the concept of community living, not on the issue of institutional versus community cost. Though in the late 1970s the notion of everyone living in the community seemed "a bizarre thing", the fact that both parents and professionals agreed made the legislators think that "they must know what they are doing." The legislature was thus able to become involved in the "same kind of learning process" that everyone else was going through in developing the community system.

One of the major changes pointed to for the future is the shifting powerbase in relationship to the legislature, and consequently to the state office. The old powerbase of an administrator was the size of the budget, the number of buildings and the number of employees over which the administrator had control. It was through these factors that and administrator

influenced the legislature. In this old system, the "customers" were state employees or agencies, and not the people who were being served.

In New Hampshire, people talked about a new shift taking place away from this orientation to a new power base called "the families." The state office now "needs" families to advocate for their budgets or the office will not exist. This shift moves "families and family support" from innovations to families as "business." It also represents a new balance that must be achieved, with the implications as yet unknown.

C. Perspectives On Change

This section presents one theoretical framework for thinking about change as raised by the key research informants. Community integration was viewed as a slowly evolving process with key "events" occurring along the way which significantly altered or shaped others that followed. This section also introduces a theoretical position on the role of individuals, including their personal values, in the change of "systems" and "society."

Systems change as an evolutionary process

Community integration was not viewed as a product or goal to be achieved, but as an evolutionary change process ("I think that state and area agency people understand that change is part of the process, that you are never done.") The complexity on the community and person level in real life meant that a long process was necessary for "real" systems change to occur. Many of the people here had labored through most of the past decade to see these systems changes - from institutional to community life - take place.

Systems change, real systems change takes a long time. It is not an overnight thing. If you are going to hire somebody and say we are going to turn this thing around in three years, it can't happen; it won't happen. You can do some superficial things and you can get things set up so they are going to work.

This notion of change was built into the New Hampshire planning process. They committed themselves not to a specific future, but to an "evolving future and a future that would be arrived at by an interactive planning process of family, consumer interests and changing needs and a recognition of the changing capacity of the state."

Critical turning points in change process

The systems change process had critical events or turning points without which the course of "history" would probably be very

different. Some of these events, like the Garrity vs. Gallen court order, were visible and widely viewed as significant given the context of the times and place when they happened. These events altered and shaped others that followed; however, they were not necessarily sufficient in themselves for the desired changes to be accomplished.

Other turning points were changes that reflected a broader way of thinking and believing on the part of a group of people, in effect a change in expectations for at least one segment of society. These turning points involved a change in the nebulous qualities of human beings, such as trust and commitment. In these instances, a few people (visionaries, leaders) "saw, felt and knew the possibilities," and "made it happen." Enough concrete changes had taken place in people's life conditions (e.g., personal connections, jobs) so that a new picture of community life could be accepted as "real."

there was this turning point. And it very hard to put a date; there wasn't a lawsuit filed; there wasn't a piece of legislation per se, but rather, we had come along far enough that we could take the flight of imagination and belief that was required in really seeing what a person's life could be. Things were approximating it enough so that we could start moving towards it.

Role of new ideas in change process

These changes and evolution came about and were encouraged in part through the infusion of new ideas and concepts, their constant repetition in diverse ways, and the real world attempts to implement these ideas in practice. The process of change included people bringing in ideas from around the country and helping others within the state to become excited and energized enough to try to make the changes in their own work, lives and communities.

Excitement raised the expectations of families, people with disabilities, agency workers, and so forth. While some people already had a vision and were committed to changing the system to better respond to families and people with disabilities, other people gradually shifted (bought in) as it became more of the norm or the general expectation. An environmental context was set up whereby people changed their attitudes and actions.

Real organizational and systems change..is...setting up an environment where people (can) change over time, change their attitudes and change the way they do things and come into conformance with the ideas and vision that people have.

This environmental context included creating opportunities, supporting the people who were really interested in being leaders - the experimenters, and then supporting others to change.

The role of the person in the change process

In this framework, the person is viewed as integral to the change process. One of the critical ways that systems change occurred was through the avenue of personal change and personal relationships ("there is no substitute for relationships with people with disabilities"). This is partially because systems themselves are so complex and unwieldy.

The point is it is easier to change people than it is to change systems. It's easier to change a person than to change a society...systems tend to think about change as, like, massive, large scale events...From my experience...a strategy of small scale changes is much more powerful.

This same informant continued describing how a life change for one person is itself a significant "systems change" strategy.

If you are going to change a system, you convince...one staff member this is a good idea. You do something on behalf of one person with disabilities...John, (a man with severe disabilities), has become a teacher. He has created an enormous amount of interpersonal and systems change by being where he is and doing what he does.

Part of how systemic changes came about were that people saw themselves and others in new ways and came to believe in new possibilities for the future. In the past decade, these visions began in special education, while now the innovations are more from the adult community services sector.

Personal beliefs and systems

Some people already have a set of beliefs that underly their work in relationship to people with disabilities. Reflective of a person's worldview, this may be founded upon a person's religion or spiritual life, family values, or on a host of other area on how people would be treated or live with one another. In contrast, a person's work could also be based upon a more disability-based concept such as community integration or normalization.

Personal beliefs were believed to be inextricably tied with systems or programs because they represented the basis for all the daily decisionmaking, which influenced a person's experience as a service user. As one informant explained, every detail evolves in a program or system from a set of beliefs, and unless this is realized, staff and managers will "miss the point."

Personal beliefs can be relevant in areas of change, where personal repercussions may befall individuals who take risks. It can be difficult for many people to take apart what they have created because it becomes no longer functional. As one informant

described how this will impact on the changes that will need to occur as the service system evolves to new stages:

We are all human...What do you do if you are an area agency director, in late 40s or 50s, been there for 8 or 9 years, it's pretty comfortable, salary's good, you get along pretty well, but now you need to restructure. And you begin to look at it, and if you are honest at all, you see there are things I have to do here to undermine the empire, and can people do that? It is hard.

The role of value based training

"Values based training" was a tool to encourage personal change and was integral to the systems change process, including the institutional closure ("it was a critical mass of people who had heard the stuff"). In this research, values based training helped people to "get off of the academic mark," start acting and then reflecting critically on what their actions meant. The hope was that people could get past their "fear of failure" and "desire for perfection" and figure out the new changes that would be necessary as people started living on their own instead of in supervised settings.

Study groups also helped to form a "subculture" similar to the experience in Georgia where such a "subculture" grew out of PASS training. This "subculture" was a network that developed from personal commitments and was "not part of the employment culture...the organizational culture." A lot of the "effective and important" work was performed, almost in underground fashion, because organizations would not always recognize these contributions as valid.

The role of personal relationships and contributions

Personal relationships, sometimes known in the literature as turf, power struggles, or personality clashes, play a central role in the change process. These relationships can either facilitate "good things" to occur for people with disabilities or they can stand in the way. One of the hidden factors in the final closure of Laconia was that the institutional superintendent and the state community services leader "played" in different arenas ("We kind of wanted the same thing, but I wasn't interested in doing the same thing he was doing.")

People also make different contributions by focusing on various aspects of the process of change. Their contributions may be structured, in part, by their job roles, such as by roles with legislators and constituents, program initiatives or community development, or fiscal and programmatic interactions. In part, people's personal capacity to contribute will also depend upon their relationships with others. Paired together or in teams,

people can accomplish over time what they could not do alone.

Systems structures and change

Planning was central during the early years of community development. However, the role of planning, in the systems sense, has changed in a field where plans become outdated before they are written and major issues in development and implementation are increasingly unanticipated.

Systems, too, have many limitations ("I think systems can set a direction, set the tone, and set up parameters to facilitate individual movement, but systems themselves don't do anything.") which highlights even more the contributions of individual people. The "system" was not expected to solve the problems and develop the solutions.

From the viewpoint of a traditional "systems approach" to change strategies, managers can build in as much flexibility as possible within a system, allowing it to adapt over time. They can also begin to "let go" of controlling features. However, while the New Hampshire system has adapted well to changes over the past 15 years ("a system that was more static would have died"), the current process of management was described as adding a "lot of bandaids" to keep it intact. The original systems design only somewhat fits the world of today.

On the state and federal policy levels, the tendency is to make visible structural changes and to assume that this means that life is better for the person. As explained by one informant, "it makes us feel better...we're just barely, really touching the whole business of people integrating into the community." The tendency on the part of professionals was described as becoming "enamored with concepts" without really knowing what was going on at the "client level." In contrast, when "things worked," there was a recognition that the "little things mattered" and that even small events or items could symbolize a "willingness to hear, to listen and to respond."

One indicator of future change is that families and "self advocates" are beginning to say that structural changes are not enough; in some cases that "our life is as dreary as it ever was." People who were used to being viewed as the "white knights" in the service system, whether at the state or agency levels, are now hearing more about the actual experiences of people with disabilities in "wonderful" programs.

The discrepancies between the experiences of professionals and service users appear to be substantial. For example, while professionals may plan for years for institutional closure or community development, people with disabilities may within days move from an institution into a "strange world." As one strong

supporter of self determination expressed, "In 10 years will we (professionals) decide...that was a mistake, we're going to send you back?" More substantial change will be necessary to assure that the institutionalization of one societal group by another will not occur again.

Society and change

Change in the lives of people with disabilities in communities means that society must also evolve. This will require very different ways of interacting with people in communities than the typical ways employed by staff members. As a starting point, communities, as represented by neighbors, coworkers and industry, must be recognized as having more capacity to accommodate differences than people within human service systems believe.

The question of societal change and whether such change is possible remains a critical, unanswered one. An informant described how a pessimist would say that someone always will play this devalued role within a society, "whether we devalue mentally retarded people, poor people or whatever or people who have blue eyes." Citing how we continue to punish people for being different, this informant explained why changing structures does not always influence these larger social forces that impact upon the lives of people with disabilities.

Our history in terms of social policy is saying nice things, but really doing bad things. At the recipient level, it doesn't feel right...I would hold that most of our social policies are based on beliefs that are somehow punitive...even when you change the structures, people play the same roles, ...you can't make it go away because...it is a larger force than simply a programmatic structure that you decide(d) on last week.

IV. Conclusion: Researcher's Views on Study Findings

In concluding this report, the researcher shares three sets of observations and areas for further study. These include: selected hypotheses for further investigation regarding change and the change process; selected areas for more indepth study regarding community integration practices; and brief comments on the relevance of these findings for research and applied assistance.

A. Hypotheses for Further Investigation on Change

This study offers the opportunity to contribute to the knowledge base on personal, systems and societal changes in both the theoretical and applied senses. The following delineate selected hypotheses regarding change and the change process, based upon this first component of the study:

1. Change is an evolutionary process that occurs over an extended period of time.
2. Critical turning points include not only specific events, but also thresholds marked by a change in set of beliefs distinct from the previous era.
3. New ideas (and their repetition) and attempts to implement these in practice are critical components to the change process.
4. Changes in attitudes and personal beliefs (i.e., personal changes) lead to systemic changes.
5. Training, action and reflection can assist in the processes of personal and systemic change.
6. By building in flexibility and "letting go" of controlling features, systemic change can be allowed to occur over time.
7. Programmatic and policy initiatives do not necessarily result in change at the level of the individual person.
8. Structural, systemic changes alone are insufficient to result in significant changes in individual life quality.
9. Community service systems built in the past decade will require major changes to achieve the next stage of community integration.
10. Multiple constituencies contribute to the change process, holding distinct roles within and outside the system.
11. The distinctions between personal and professional perspectives are critical to address in moving toward the next stages of community development.
12. Personal and societal change are essential for full integration to occur.

B. Areas for Further Study on Community Integration Practices

While numerous areas exist for further study, the following represent several examples of areas to explore:

1. Informal talk networks and working relationships. Since systems change may be tied with the individual or person level of change, a more indepth investigation of relationship patterns and how they "work" may be beneficial to the field. The study suggests that many changes are on the horizon, and that practitioners of this decade will be in the role of making challenging decisions that will call not only on their professional skills, but on their personal and interpersonal strengths.

2. Grassroots coalitions/shifting power base. This appears to be a major mechanism for substantive societal change and an indepth investigation of the patterns and effects in the disability field may be useful. How and if such realignments occur can effect the nature of the relationship between service users and agencies in the decades to come.

3. Patterns of shifting practices. The patterns and processes of shifting patterns in the field is worthy of further study both from the perspective of causative factors and of the relationship of the shifts in emphases (e.g., from employment to family support to home ownership). In particular, there is a need to pursue how and why these changes come about, including their ties with financing, lead agency, technical assistance and philosophical changes in the field.

4. Role of new ideas. It is unclear how new ideas come to the attention of people in the field, including policymakers, and how they also fade from view. Understanding these dynamics are critical to long term, fundamental changes versus those that may result in surface or transient changes. This area also holds important implications for the replication framework currently predominant in the disability field, suggesting instead an evolutionary approach to change.

5. Leadership. While leadership has been an intensive area of study, many aspects of it are still not well understood. In particular, the roles of individual people in non-hierarchical roles, the ways in which women and those with diverse backgrounds multicultural backgrounds lead, and the fusion of personal and professional strengths need to be better explored and articulated.

6. How systems work. Probably the most important aspect of the study is to explain "how systems work" not only as presented by those in control of these systems, but also from diverse viewpoints. This can provide the information to help people to better understand how to work together in moving to the next generation of community life. It can also assist in identifying specific target areas for change, such as "ossification" of service systems, and critical areas for skills development, such as administrative skills in "dismantling" what exists.

7. Interrelationship of categorical groups. There are indicators in this first study component about the importance of enlarging the scope to include cross population research, inclusive of people with head injury, elders and those involved with the mental health systems. Issues for competition for resources and implications for cross-systems reorganization are critical areas for further examination.

C. Relevance of Research and Findings

In the disability field, there have been few opportunities to conduct intensive, field-based research studies that can assist on a long term basis in the development of strategies, practices and policies that can positively impact upon the lives of people with disabilities. This research provides several key opportunities which include:

(1) To make available diverse perspectives to a broader group of people on contributions of various organizations and people to the change processes (i.e., increasing the base of people who hold knowledge on "how things work");

(2) To examine "taken for granted assumptions" particularly as held within the system and to analyze whether these patterns are inherent or can indeed be subject to change for the betterment of society's members;

(3) To record the history of experience and learnings in the community movement as a base for the next generation to develop their agenda regarding the way in which people with and without disabilities will choose to live in society.

One of the critical decisions regarding this study is to continue to focus on developing a solid research data base, resisting the tendency to follow one of the two traditional routes in this field of either short term applied policy implications or broad-based sociological implications. Instead, this study presents an opportunity to explore the middle ground, bringing the expertise of diverse disciplines and backgrounds to bear on the challenges of how we will live together in the decade to come.

The disability field is at a time of potentially significant change, which can either result in mechanistic surface changes, or can become a path for more fundamental, substantive personal, community and societal change. This study holds promise to differentiate between changes which primarily maintain or develop the employment culture and those changes which will be essential in moving toward communities and a world where all belong and are valued.

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³ The reader can also request a bibliographic listing of all New Hampshire documents reviewed for this study.

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